

## Iowa Autism Council Meeting Final Minutes 06/08/2016

Meeting minutes taken by **Beth Buehler-Sapp**

- Present:** James Curry, Erika Hertel, Matthew O'Brien, Jeffrey Jennings, Angela Burke-Boston, Theresa Croonquist, Brandon Reece-Arkland, Connie Fanselow, Wendy Trotter, Sean Casey, Rachel Heiss, Steve Johnson, Tara Underwood-Levin, James Paprocki and Beth Buehler-Sapp.
- Absent:** Mary Jackson, Steve Muller, Angela Logsdon and Becky Harker.
- Guests:** Peggy Swails from Child Health Specialty Clinics @ the UIHC RAP Program.  
Chase Smith and Steve from Amerihealth Caritas.  
Angela Pretz from UIHC-RAP program.
- Zoom:** Frank Kohler, Jenny Phan, and Jan Turbes

James Curry called the meeting to order at 10:10 am. Participants introduced themselves and welcomed new member, Jim Paprocki.

Council Members reviewed the draft minutes from the March 9, 2016 meeting. Erika Hertel made a motion to approve the minutes and James Curry seconded the motion. Minutes approved.

Council Members reviewed the 2016 Priorities and Recommendations report that was submitted to the legislature and discussed status of the following listed priorities:

- Iowa Strategic Plan – 2016-2021: To Improve Services and Supports for Individuals with Autism Spectrum Disorder and their Families. – Strategic plan is complete. Will ask for regular updates from the field regarding progress of goals in the plan.
- Amendments to the Autism Support Program (ASP) –
  1. Amend income qualification guidelines – this has now been changed to “not to exceed 500% of the federal poverty level”.
  2. Amend age limit to age 21 – this has been changed to age 14.
  3. Increase reimbursement rates – this did not change.
  - Additional change included in approved bill (indicated in underlined text): “... cost-sharing shall be applicable to individuals with household incomes at or above two hundred percent of the federal poverty level in incrementally increased amounts up to a maximum of ~~ten~~ fifteen percent....”
- Insurance Mandate – Council had encouraged the Governor and Legislature to pass a private insurance reform that would expand coverage for ASD treatments to include all plans regulated by state insurance rules. House File 2112 was introduced which was “An Act requiring certain group health insurance policies, contracts, or plans to provide coverage for autism spectrum disorders for certain persons, providing for a repeal, and including applicability and effective date provisions, be enacted by the general assembly of the state of Iowa.” It was reported that

this did not make it out of funnel. House then added this to the appropriation bill, but Senate did not pass.

Other legislative updates related to ASP include:

- BCBA/BCaBA grants program – An additional \$250,000 was appropriated to this fund, which was added to the unexpended moneys from last fiscal year, which equates to a current total of \$500,000 which will not revert. Rules are currently still in development. This fund is housed with the Department of Public Health. The following are changes included in the approved bill (added language is underlined):
  - “...applicants who have been accepted for admission or are attending a ~~board of regents~~ university, community college, or an accredited private institution, within or outside the state of Iowa, are enrolled in a program that is accredited and meets coursework requirements to prepare the applicant to be eligible for board certification as a behavior analyst or assistant behavior analyst, and demonstrate financial need.
  - “The applicant shall agree to practice in the state of Iowa for a period of time, not to exceed four years, as specified in the contract entered into between the applicant and the department at the time the grant is awarded. In addition, the applicant shall agree, as specified in the contract, that during the contract period, the applicant will assist in supervising an individual working toward board certification as a behavior analyst or assistant behavior analyst or to consult with schools and service providers that provide services and supports to individuals with autism.”
  - “... Priority in the awarding of a grant shall be given to applicants who are residents of Iowa.”
  - “... The amount of funding awarded to each applicant shall be based on the applicant’s enrollment status, the number of applicants, and the total amount of available funds. The total amount of funds awarded to an individual applicant shall not exceed fifty percent of the total costs attributable to program tuition and fees, annually.”
- Appropriations - \$2,000,000 were credited to the Autism Support Program fund, with the exception of the \$250,000 for the BCBA/BCaBA grants program, and \$50,000 for the pilot project grants for serving individuals with autism.

#### ASP Updates:

Income level and age were the two most common reasons applicants have been denied. Connie Fanselow reported that 3 applicants in last 3 months were denied due to income cap, but they have contacted those families and suggested they reapply after 7/1/16 when legislative changes go into effect.

Connie Fanselow also suggested providers encourage clients that could now be eligible due to the age increase of up to 14 years to reapply for ASP funds.

#### BCBA/BCaBA Grant:

There was much discussion about the status of the BCBA/BCaBA Grant program. It was asked what institutions in Iowa offer a BCBA education program. Sean Casey reported that Briar Cliff University

currently has a two-year BCBA program. Sean also reported that Drake hopes to offer a BCBA program in the 2017-18 school year.

Matt O'Brien reported that University of Iowa will offer a BCBA program beginning in the Spring 2017 semester.

#### Regional Autism Assistance Program (RAP) and CHSC updates:

Peggy Swails informed the council of CHSC and RAP's application for a funding opportunity sponsored by The Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), and Division of Services for Children with Special Health Needs entitled "Innovation in Care Integration for Iowa's Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities Program". Notification of those awarded the grant funding will occur somewhere between mid to late August and September 1, 2016.

Additional information regarding this grant was provided in a presentation. Key information included:

#### Executive Summary

- The purpose of this program is to support the implementation of strategies to integrate care at a state system level for children and youth with autism spectrum disorders and other developmental disabilities (ASD/DD).
- This program will have a special emphasis on improving care for children and youth with ASD and other DD in medically underserved populations.
- The target population for this program is *all children and youth within a state identified as at risk for or diagnosed with ASD/DD*.

#### Timeline

- Grant guidance released March 8, 2016
- Application submitted May 10, 2016
- Estimated award amount is \$420,000/year
- Anticipated notice of award: Mid-August 2016
- Up to six (6) states will be awarded
- Project period extends three (3) years:  
September 1, 2016 through August 31, 2019

#### Program Goals (from HRSA guidance)

- Improve access to a coordinated, comprehensive state system of services that leads to early diagnosis and entry into services for children with ASD/DD within the state and their families, emphasizing medically underserved and rural populations.

#### Program Objectives (from HRSA guidance)

- **Objective 1:** By August 31, 2019, increase the proportion of children within the state identified as at-risk for ASD diagnosis and referred for diagnosis and ASD/DD services by 25 percent over baseline.
- **Objective 2:** By August 31, 2019, increase the percentage of children with ASD and other DD within the state enrolled in services before 37 months of age by 10 percent over baseline.
- **Objective 3:** By August 31, 2019, increase the percentage of children with ASD/DD residing in medically underserved communities within the state (based on poverty, rural, and/or populations that experience health disparities) enrolled in services before 37 months of age by 10 percent over baseline.

- **Objective 4:** By August 31, 2019, increase the proportion of children and youth with ASD and other DD within the state and their families by 25 percent over baseline who report increased knowledge, skill, ability and self-efficacy in family-centered care; specifically related to referrals, diagnosis and access to services for ASD/DD (with a special emphasis on medically underserved populations).
- **Objective 5:** By August, 31, 2019, increase the number of referrals of at-risk children for ASD/DD within the state to early intervention programs and/or specialists for comprehensive evaluation by 25 percent above baseline.

#### Program Requirements *(from HRSA guidance)*

- Establish a multidisciplinary project advisory group made up of stakeholders, including families and experts who have specialty background and experience in ASD/DD.
- Use innovative, evidence-informed strategies to improve access to a coordinated, comprehensive system of services for children and youth with ASD/DD.
- Each evidence-informed strategy must include family engagement activities to ensure partnership between ASD/DD families and providers.
  - Shared Resource
  - Telehealth/telemedicine/mhealth
  - Family Navigators
- A minimum of twenty percent (\$84,000) of the project budget will be used for performance monitoring and to develop a comprehensive evaluation plan incorporating national, state, and community data.

#### Project Aim *(per CHSC application)*

- To improve access to a coordinated, comprehensive state System of Care leading to early diagnosis, timely entry into services, positive transition experiences for children and youth ASD/DD and their families, while assuring access to Family Navigators, and extending services into medically underserved communities in Iowa.

#### Project Goals

- **Goal 1:** Increase the number of Iowa children identified as at-risk for ASD/DD diagnosis, referred for comprehensive diagnostic assessment, early intervention services, and family-to-family support.
- **Goal 2:** Increase access to diagnostic and intervention services for children with ASD/DD and their families residing in medically underserved communities.
- **Goal 3:** Increase the knowledge of families about referral sources for family support, intervention strategies and services, funding sources for intervention services, and transition resources and services.
- **Goal 4:** Increase statewide integration to enhance the system of services and supports for children and youth with ASD/DD and their families.

Peggy will keep the council informed of the outcome of their application.

#### Council members had further discussion of insurance reform –

Angela Burke-Boston explained that the insurance reform bill that was proposed (HF2112) would not have covered everyone, only the carriers of individual and small group policies (a company that has 50 or less employees is considered a small group) because they are regulated by the Iowa Insurance Division. But large group (companies that have 51 or more employees) are not regulated by the Iowa Insurance Division.

Currently many companies offer coverage for some therapy services, but there is no state requirement to cover ABA services. Carriers can make the decision if services are “medically necessary”.

There was further discussion regarding how services are deemed “medically necessary”. James Curry asked, “What are the objections to ABA services and what hump do we have to get over to get this to be a universally provided service?” Also, “At what point does something become medically necessary?” Jeffrey Jennings asked, “If something is a covered benefit is it medically necessary?” This is a tricky subject and there can be a lot of variation from one company to another.

Frank Kohler thought that perhaps the council should invite someone to come and talk about insurance reform. James Curry asked, “Do we want to invite someone from Autism Speaks to come to the September meeting?” The council had further discussions and decided to table the discussion for now.

#### ABLE Act –

A member of the council asked about the status of the ABLE Act. The ABLE Act amends Section 529 of the Internal Revenue Service Code of 1986 to create tax-advantaged savings accounts for individuals with disabilities. These tax-advantaged savings accounts can be used to cover qualified disability expenses such as, but not limited to, education, housing and transportation.

The bill supplements, but does not replace, benefits provided through private insurances, the Medicaid program, the Supplemental Security Income program, the beneficiary’s employment and other sources.

Currently, we are waiting for the federal rules before initiating in Iowa.

Brandon Reece Arkland brought up the idea that perhaps we could approach legislators from a different angle and find a way to meet with them and share personal stories from adults with ASD and how services could have benefited them. Perhaps that could open a door to real conversations about why we need reform.

It was reported that on November 4<sup>th</sup> Gina Green, a renowned expert on ABA services, will be presenting at the Iowa ABA conference here in Des Moines. If anyone interested in more details they should go to [iowaaba.com](http://iowaaba.com).

Angela Burke-Boston made a motion to adjourn the meeting and Theresa Croonquist seconded the motion. Meeting adjourned at 3:00 pm.